FACILITATED COMMUNICATION VIDEO DISCUSSION GUIDE

to accompany

- "We Have a Lot to Offer": An Introduction to Facilitated Communication
- "A Part of our Life": Facilitated Communication with Pre-School Age Children
- Facilitated Communication in the School Years
- "A New Beginning": Facilitated Communication for Adults
- Facilitated Communication for Family and Friends

Marilyn Chadwick
Douglas Biklen
Mayer Shevin

Facilitated Communication Institute
© Syracuse University
1993

These videotapes and discussion guide
are dedicated to those
who struggle to let others know
that they have something to say,
and who continue with courage
to share their ideas
with the rest of the world.

TABLE OF CONTENTS

Introduction i
Description of the videotapes i
Acknowledgements iii
How to use this guide iv

SECTION I 1
What is facilitated communication? Who is it for? 2
Validation 2
Getting started 4
Prepare activities 4
"Climbing the ladder": activities leading to free communication by spelling 5
Explain method clearly 6
Select a comfortable position 6
Provide physical support 7
Practice pointing 10
Monitor eye contact with the keyboard 10
Fade to minimum support 11
Give encouragement 12
SECTION II 13
Common questions and answers about the method:
With whom should it be tried? 14
Knowing that it is real -- looking at research 16
Developing peoples' skills 16
Worksheets:
II-1: Choosing a candidate 20
II-2: Simulation 21
SAMPLE LETTERBOARD 22
II-3: Respectful Attitudes 23
SECTION III 24
More common questions and answers about the method:
Using facilitated communication in the real world 25
Worksheets:
III-1: Making it work 27
III-2: Fostering literacy 28
III-3: Facilitated Communication in inclusive settings 29
III-4: Changing roles 30
SECTION IV 31
Appendix I: Resources for setwork 32
Appendix II: Problem-solving facilitated communication 33
Appendix III: Equipment 34
Bibliography 35
ORDER FORM 37

INTRODUCTION

Facilitated Communication is a means of "facilitating" expression of people who either do not talk or do not talk clearly and who cannot point independently and reliably. Rosemary Crossley, educator and founder of the DEAL Communication Centre in Melbourne, Australia, is recognized as the originator of the method. She believes that for people with various communication disabilities, the problem of communication may not be essentially cognitive or receptive, but is rather a difficulty with expression.

In January 1990, Douglas Biklen, Professor of Special Education at Syracuse University, began to use the method in Syracuse schools and community settings with students labelled autistic, ranging in age from three years nine months to 25 years old. All of the students either did not speak or had speech comprised of echoes. Most of them had previously been presumed to have intellectual disabilities. With facilitation, these people could point to letters and thus construct words, phrases, and sentences. They produced natural language through their typing; they demonstrated unexpected literacy and numeracy skills. While their expressive abilities varied considerably, facilitated communication allowed for better communication than they had previously achieved. After these initial efforts, use of the method was expanded to individuals with a broad range of developmental disabilities.

In July 1992, Syracuse University established the Facilitated Communication Institute to pursue goals of continued research, training, and public awareness. As part of this work, these five videotapes and discussion guide serve as introductory material for understanding the concept and application of facilitated communication. Beginning with an overview, and then developing the concept for specific age groups, the videotapes highlight people with various disabilities. They were produced by the Academy Award winning documentary producer Gerardine Wurzburg, of State of the Art, Inc.

TO ORDER, OR TO OBTAIN INFORMATION ON OTHER PUBLICATIONS AND VIDEOTAPES, SEE PAGE 37.

❖ ❖ ❖ ❖ ❖

The Videotapes:

"We Have a Lot to Offer": An Introduction to Facilitated Communication

This overview includes interview footage of the Australian educator, Rosemary Crossley, and American educator Douglas Biklen as well as the thoughts of parents, teachers, and individuals who use facilitated communication to express themselves. The video includes background on the method, a rationale for why some people with disabilities are helped by this approach, suggestions for which individuals may find it useful, information on how to determine that the method is working, and a discussion of how to confirm that the words typed are those of the individual with the communication disability.

"A Part of Our Life": Facilitated Communication with Pre-School Age Children

Filmed primarily at the Jowonio School in Syracuse New York, this video describes how to introduce facilitation to young children with various developmental disabilities. The classroom scenes all include children with and without disabilities. The video provides portraits of five children who use facilitated communication to express their thoughts and feelings.

Facilitated Communication "In The School Years"

Filmed in an elementary school, middle school, and high school, this video introduces the method and explores how students can be supported in regular classes to communicate and participate. Teachers explain how they adjust their teaching approach to help students using facilitation to succeed in their classrooms. The video shows peers, parents and siblings, as well as teachers and teaching assistants facilitating. A school principal discusses how administrators can support implementation of facilitation in the school.

"A New Beginning": Facilitated Communication for Adults

This video describes how facilitated communication is enhancing the lives of adults living in the community. It features three adults, providing portraits of how they use facilitation in their daily lives. The video explains how to get started with facilitation, including some hints at working on independent typing, and how to support people using facilitation in different community settings. The title of this video, "A New Beginning," is how one of the three people featured describes the meaning of facilitation for her.

Facilitated Communication with Family and Friends

This tape is based on the experiences of several families and friends. It describes how they got started, how they continue using facilitation, and the changes it has brought. It focuses on the impact of facilitation on family relationships and the opportunities it provides for developing deeper personal friendships. Families describe how facilitated communication can cause roles to be redefined, routines to change, and inclusion to be broadened. The tape shows how facilitated communication can be a crucial element in people gaining greater self determination.

ACKNOWLEDGEMENTS

The videotapes and discussion guide have been made possible through the support and effort of many people. Many thanks are extended to those people who contributed in various ways to the development of the videotapes and discussion guide:

Yvonne Ahokovi, Ellen Barnes, Mac Beneway, Johnny Cambareri, Nancy Centra, Roger Cherry, Zan Currin, Shaheim Davis, George Deloff, Kim Dence, Michele Dimon-Borowski, Jinny Ellis, Ed Erwin, Pat Floyd, Adele Freeney, Nereida Gonzalez, Kathy Goodman, Sue Harms, Patricia Howard, Kimberly Iwanski, Pam Johnson, Patty Johnson, Chris Judge, Lori Keevil, Sandy Ladd, Ronald Lanaux, Lori Lawless, Galyn Lyden-Murphy, David Marcus, Gene Marcus, Thomas McGowan, Shaun McGuane, Chip Miller, Richard Odom, Timothy Pitcher, Jeffrey and Sharon Powell, Jeff Powell, Teri Priest, Ceres Ross, Chris Santimaw, Darcie Tamburo, Calvin Washington, Sandra Wiggins, Henry Williams, Anne Winschel, and Holly Winschel.

We would like also to acknowledge those organizations who opened their doors to the process of film-making.

Acropolis Pizza House
Baker High School
Byrne Dairy
Christie's Lake House
Edward Smith Elementary School
Hills Department Store
Jowonio Pre-School
Levy Junior High School
Monarch Industries, Inc.
Onondaga Association for Retarded Citizens
Petit Library
Pioneer, Inc.
Syracuse Developmental Center

We would like to recognize Gerardine Wurzburg and Grady Watts with the State of the Art, Inc. for their artistic and technical expertise in film-making.

A special thanks goes to those at Syracuse University who have worked to understand and share facilitated communication with others:

Rosemary Alibrandi, Carol Berrigan, Bob Bogdan, Marilyn Chadwick, Neal Coffey, Stephan Drake, Janet Duncan, Deb Gold, Margaret Hardardottir, Elaine Karp, Chris Kliewer, Arlene Knoblauch, Sue Lehr, Sherry Lord, Missy Morton, Marj Olney, Lynn Roberts, Nina Saha, Annegret Schubert, Mayer Shevin, Robin Smith, and Michelle Sures.

We are very grateful for the generous support of the administration of Syracuse University, without which this project would not have been possible. We are especially indebted to Kenneth Shaw (Chancellor), Mary Ann Shaw, Stephen Bossert (Dean of the School of Education), and Wendy Harris.

Most of all, we are indebted to Rosemary Crossley and DEAL Communication Centre for introducing us to Facilitated Communication and guiding our understanding.

--Douglas Biklen

HOW TO USE THIS GUIDE

You will be viewing one or several videotapes on Facilitated Communication. These tapes include people from preschool age through adulthood who have severe communication impairments. Many of them are nonverbal. Some of them have some speech but can use it only in limited ways. Through facilitated communication they are able to share their thoughts, convey their feelings and participate in life situations more fully. These glimpses of people's lives show the daily effort of those who use the method of facilitation for communication. These people are successful because of their own diligence and the support of many people around them. As you view the videotapes, you are invited to learn about the method, and begin to develop these kinds of support for a person you know.

This discussion guide has been developed to further your understanding of the concept of facilitated communication. This guide is divided into three sections. **Section I** gives explanation of what facilitated communication is, who to use it with, and how to introduce it. **Section II** and **Section III** are designed to answer questions and foster group discussion. The discussion guide and the videotapes should be used together so that you have complete information.

The video *"We Have a Lot to Offer": An Introduction to Facilitated Communication* can best be used as an introduction to the other tapes and the activities in this discussion guide.

For any of the age-specific tapes (*"A Part of our Life": Facilitated Communication with Pre-School Age Children*, or *Facilitated Communication in the School Years,* or *"A New Beginning": Facilitated Communication for Adults*), the following format is suggested:

1. Read through Section I of the discussion guide.
2. View Part I of the videotape.
3. Discuss questions and answers from Section II of the discussion guide; add your own questions.
4. Use one or all of the worksheets from Section II of the discussion guide.
5. View Part II of the videotape.
6. Discuss questions and answers from Section III of the discussion guide; add your own questions.
7. Use one or all of the worksheets from Section III of the discussion guide.

Finally, the videotape *Facilitated Communication with Family and Friends* can best be used by first watching the tape, and then working through **Section III** of this discussion guide.

The videotapes can be used in a variety of ways with various size audiences. Optimum use, however, would foster an opportunity for small group discussion and sharing. It is important that everyone can participate, raise questions, and share their ideas and experiences.

❖ ❖ ❖ ❖ ❖

SECTION I

BEFORE YOU VIEW PART I OF THE VIDEOTAPE, TAKE TIME TO READ THE INFORMATION IN THIS SECTION. SOME OF IT REFLECTS THE EXACT WORDS OF THE SPEAKERS ON THE VIDEOTAPE. THERE IS ALSO FURTHER EXPLANATION TO HELP YOUR UNDERSTANDING. FEEL FREE TO REREAD THE TEXT AFTER YOU HAVE VIEWED THE VIDEO.

WHAT IS FACILITATED COMMUNICATION? WHO IS IT FOR?

Facilitation is a way to enable people who have limited or no speech, and physical disabilities which prevent reliable independent pointing, to express themselves through physically supported use of letterboards and keyboards. For very young and preliterate children, pictures and symbols can be used as well. Facilitated communication can also help people with limited speaking ability to express more complex ideas.

In each of the videotapes, you will see people of all ages, of various disabilities, being physically supported as they point to letters on several types of devices. Some are supported at the hand, while others are touched at the wrist, arm or elbow.

For each one of these individuals, someone wondered if facilitation would benefit his/her communication. It may have been a teacher, case worker, mom or dad. In making the decision of whether or not to try, these people looked past the label and thought about how these individuals communicated, how they moved and used their hands, what some of their behavioral difficulties were, and how these individuals gave a sense of understanding what was being said.

The decision to try should be viewed as an opportunity, a chance to see if a person's ability to communicate is being masked by an ineffective, unreliable movement pattern. There is a natural tendency to ask such questions as "Can he read?" or "Does she understand that concept?" These are not the issues of candidacy. A person does not need literacy skills for an effective pointing strategy nor abstract reasoning for simple choice making. As the opportunity for more effective and reliable pointing is offered, questions of literacy and comprehension can be addressed.

❖ ❖ ❖ ❖ ❖

VALIDATION

"(Darcie) was in school one day and facilitating with Michele and she was telling Michele about a dog named Happy. Michele said, Darcie I think you're fibbing because I've been to your house and there's no dog. Two days later I spoke with Michele and she mentioned it and I said, but Michele, we had a dog named Happy when Darcie was a little girl."

--Jinny Ellis,
"We Have a Lot to Offer,"
An Introduction to
Facilitated Communication

Darcie and others on the videotapes have given numerous examples that they are communicating through the typing. For each person, this happens on a regular basis through natural circumstances. When put all together, these situations provide a profile of the person typing as one who is the real communicator. As you use facilitation with someone, it is helpful to look for these examples and make note of the circumstances. Things to look for can include:

- ☼ Phonetic and creative spelling revealed across different facilitators;
- ☼ Actions that reflect typing (e.g. getting a

drink of water after typing about same);

- ☼ Recurring topics, recurring phrases revealed across different facilitators;
- ☼ Independent use of delete key, space bar, carriage return at appropriate time;
- ☼ Speech improvement; saying letters before they are typed or just after being typed;
- ☼ Eye gaze; looking at keys before striking them;
- ☼ Conversational style (e.g. humor, seriousness);
- ☼ Unexpected content (e.g. swearing, unusual choice);
- ☼ Patterns of typographical errors;
- ☼ Initiating communication (taking out communication device, pointing finger, initiating first letter of word);
- ☼ Attending ability;
- ☼ Improved behavior;
- ☼ Conveying information not known to the facilitator but which can be verified;
- ☼ Independence, no physical support

It is natural to wonder who is communicating when you first witness facilitated communication. Especially as new knowledge and skills are revealed, it is often hard to believe that the person with a disability is the one who is communicating. Many people begin with doubts in their minds. What is important is how you respond to the wonder and the doubt.

Using facilitated communication means offering an opportunity to someone. That is very different than giving them a test to see if they qualify. In order for it to be a true opportunity, you must have an openness toward any and all outcomes. It's an attitude of letting that person show you what is possible, and thinking about how you can best support their ability to respond.

"Our goal here is not to find out how smart somebody is, but to give the person successful experiences with this as a means of communication."

--Doug Biklen
Facilitated Communication:
"In the School Years."

❖ ❖ ❖ ❖ ❖

GETTING STARTED

Each person on the videotapes went through a "getting started" process. It was a time of growing for both the facilitator and the person requiring support. For some, this time was short, and their skill developed continuously and rapidly. For others, this time was long and required persistence on the part of both people in learning how to work together.

Here are points to think about in getting started:

1. PREPARE ACTIVITIES

On the videotapes, you will see a variety of natural life situations which offer opportunities for getting started. Gene Marcus, an adult, responds to choices for lunch given at the restaurant. Chris Judge works on a spelling lesson in school. Holly Winschel makes choices when wrapping a gift for a friend. Roger Cherry plays "garage" with a preschool classmate. By looking at a person's day, or at the kinds of things that other people of the same age do, we can find endless possibilities.

"One of the first key pieces of good facilitation is having an attitude of believing in the child -- and it doesn't necessarily (mean) believing that they are going to start communicating in full sentences -- but believing that the child has something to offer, and that our support, both physical and emotional, is going to be one of the ways to help kids communicate what they are able to."

--Zan Currin
"A Part of Our Life":
Facilitated Communication
with Pre-school Age Children

It is mentioned on the videotape that simple and predictable work is often helpful in the getting started process. This is called **set work.** It allows a greater degree of success and helps build the confidence of the facilitator and the person who is typing. It also allows the facilitator to gain a sense of the person's speed and movement pattern when typing. In short, it gives the facilitator a "feel" for how to support. All the situations mentioned above can be considered types of set work.

In facilitation training, Rosemary Crossley uses this structured format which starts with simple pointing interactions and builds, like a ladder, toward complex communication. This helps facilitators to see what is next, as well as how to offer the communication differently to develop natural, effective communication. An example of the ladder can be found on the next page. Resources for setwork can be found in Appendix I (p. 32).

It is not necessary to start at the bottom of the ladder. The facilitator needs to provide opportunities at various levels and help explore which levels are most successful. One person may begin with copying words, while another with sentence completion. A person may use whole word pointing in one situation and multiple choice in another. In each session, the individual should be given the opportunity to progress from a simple response to a more complex one. This can be done by asking the person: "Is there anything else you would like to say?"

CLIMBING THE LADDER

Activities Leading to Free Communication by Spelling

Self-initiated conversation, where the users get their aid or ask for it without any prompt.

↑ or ↓ Spontaneous conversation, where the topic is chosen by the user.

↑ or ↓ Wide-ranging conversation (encouragement to use a range of sentence structure may still be necessary: "Now you ask me a question.")

↑ or ↓ Answering questions -- "What did you do over the weekend?" or "How did you like the movie?"

↑ or ↓ Typing sentences in a set context -- picture captions, describing pictures, speech balloons for cartoons.

↑ or ↓ Exercises with a limited range of answers -- "Give me a word that rhymes with 'day'," or "Give me the opposite of 'big'."

↑ or ↓ Completing common sentences or phrases -- "Fish and _____," or "Too many cooks spoil _____ _____."

↑ or ↓ Cloze exercises -- "Put the missing word in the sentence: Bob _____ a car."

↑ or ↓ Exercises with set answers known to the receiver -- crosswords, general knowledge questions, names of friends or family.

↑ or ↓ Typing set words -- "Spell 'horse'," or labelling household items or pictures.

↑ or ↓ Copy typing -- "The quick brown fox jumps over the lazy dog."

↑ or ↓ Replacing missing letters in words -- perhaps on the Talking Lesson One or Speak and Spell computer toys.

↑ or ↓ Word matching -- bingo, lotto, word association games (group activity only)

↑ Yes/no, true/false, and multiple choice -- simple quizzes, (Do dogs go meow?"; "Type C if you want coffee and T if you want tea."

(Adapted from: DEAL Communication Centre, 1992, p.13)

2. EXPLAIN METHOD CLEARLY

"I would give them a brief explanation.... what it is that I want them to try, mostly just by saying that...this is a method of communication that some people who have trouble speaking clearly have found helpful."

--Sue Harms
Facilitated Communication: "In the School Years"

"I really explain to kids why I'm doing that, it's not that I'm testing them. I talk to them about other kids that are typing to me, I may show them typing of another kid, if it's okay with that kid."

--Lori Lawless
"A Part of Our Life": Facilitated Communication with Pre-School Age Children

It is important to explain what you want to do with the person who will use the typing. Use examples of others' spelling to describe the method. If possible, use photographs and/or show possible devices that you might be using with the individual. Teenagers and adults benefit from viewing a videotape about facilitation. The explanation should make clear that this is something that you think they can be successful with. Use words and body language which acknowledges their understanding and gives encouragement.

3. SELECT A COMFORTABLE POSITION

Across the videotapes, you will see various positions used to support people in the typing. It is important that both the facilitator and the person typing are comfortable.

"I don't believe that there's any fixed position for facilitated communication. I believe that the more flexible you are and the sooner you realize that, the more you're able to incorporate facilitated communication in everyday life because that's what it's all about -- communicating.

--Jinny Ellis
"A New Beginning": Facilitated Communication for Adults

Here are a few considerations when establishing that position for the first time.

1. Position the letterboard/ device so that the person using facilitation can easily see the letters.
2. If possible, use a table that is low so that the movement to the letters is a downward motion.
3. Think about limitations which may exist for range of movement.

4. Position yourself so that you can see the letterboard as well as monitor the person who is typing.

> "A lot of times when I'm using facilitation with a child, that child is sitting in my lap, and a lot of times I'm also really wrapping myself around that child because that helps them maybe be in control of muscles that they wouldn't otherwise be able to control on their own and then they can be concentrating on just the communication and the pointing."
>
> *--Zan Currin*
> *"A Part of Our Life": Facilitated Communication with Pre-School Age Children*

> "The touch has to be even and consistent and show that you have a great deal of confidence that you can facilitate them and you also have to carefully pull back after each key is struck by the person who you're facilitating."
>
> *--Dave Marcus*
> *"A New Beginning": Facilitated Communication for Adults*

4. PROVIDE PHYSICAL SUPPORT

On the videotapes you will notice that different people are being given different support. Some people who communicate through facilitation receive different levels of support from two different people. Differences can also occur with the same facilitator in two different situations. Roger Cherry is supported at the hand or wrist by his teacher, but can also spell some words without any support. Gene Marcus is given support at the hand by his father, and can type at open conversation with another facilitator giving a light touch to his elbow. Facilitated communication is not just physical support but a combination of physical and emotional support together. Dave Marcus highlights this thought as he speaks about getting started with his son Gene:

Here are factors which are important in successfully supporting facilitation:

- ☼ Identify left or right handedness
- ☼ Stabilize the arm or hand
- ☼ Isolate index finger
- ☼ Apply backward resistance
- ☼ Pull back after each selection
- ☼ Never guide to a selection

When a facilitator provides physical support, he/she gives resistance, or backward pressure to the person's hand, wrist, or arm. The purpose in doing this is to stabilize and slow down the movement pattern of the person requiring support. It also helps to keep that person focused and on task. It is important to emphasize that the facilitator is applying pressure **against** the movement of the person who is typing. The facilitator NEVER moves the hand of the person using facilitation, but provides the opportunity and encouragement for that person to make his/her own movement, and then assists that movement with gentle, firm, **backward** pressure.

There are many reasons why the individual may need this type of support. Rosemary Crossley, founder of the DEAL Communication Cen-

tre in Melbourne, Australia, has helped us understand hand function issues.

1. **Poor eye-hand co-ordination: The person using facilitation finds it hard to both look and move at the same time.**
   Encourage the person to look; wait until his/her eyes return to the letterboard before you allow movement to occur. Practice looking and moving with routine spelling such as name, address, etc.

2. **Low muscle tone: The person typing has a "heavy" arm and the movement appears "floppy."**
   Give support from under the forearm or at the palm of the hand. Also try supporting from the top of the forearm and giving verbal encouragement to move and pull back. Avoid supporting from under the wrist as this may cause a bending at the wrist that will interfere with the development of independent movement. If starting at the hand, move toward support from above the arm, or holding the sleeve. Keep letterboard low so that speaker can use a drop movement.

3. **High muscle tone: The person typing uses a quick, forceful, seemingly impulsive movement. The arm is stiff and can lock at the elbow.**
   Encourage the person to slow down; use a calm and quiet voice. Give increased resistance to help develop an even and rhythmic movement. Keep the elbow in a flexed position, either by having the speaker touch his/her chest or other support to the upper arm to keep it close the body.

4. **Index finger and extension problems: The person using facilitation has difficulty extending the index finger while holding back the other fingers. Some have trouble altogether, while others can extend the finger, but not maintain the position.**
   It is important to employ a variety of techniques to help with this issue. These might include: stimulating the fingerpoint before beginning facilitation by touching the end of the person's finger; giving the person typing something to hold with the other fingers; giving consistent verbal encouragement to get the finger ready; providing activities which strengthen the use of the index finger (getting soap from a liquid soap dispenser). Facilitation may need to be started with a full wrap of the hand but should be faded to less support as soon as possible, within the first few sessions.

5. **Perseveration: The person typing makes the same letter selection over and over, inappropriately.**
   Pull the person's hand back and give verbal encouragement to move on to the next selection.

6. **Using both hands for a task only requiring one: The person using facilitation tries to use both hands while typing. In other activities, he/she may use both hands to eat or handle small objects.**
   Try to determine as clearly as possible which hand is the dominant one. Give verbal encouragement to keep the other hand in the lap. Allow the person to hold something in that hand. In some cases the facilitator may need to provide physical support to the other hand, helping the person to hold it down. This level of support should be faded as soon as possible.

7. **Tremor: The person typing tends to shake or tremble as he/she moves toward the spelling device.**
   Use firm backward pressure to stabilize

the person's movement. Keep the device low so that the speaker can benefit from a drop motion rather than an outward motion. Explore the possibilities of light weights at the wrist.

8. **Radial/ulnar muscle instability: As the person typing moves toward the spelling device, the index finger swerves away from the intended target and hits a letter next to, above or below it.**

   First the facilitator needs to observe and gain a sense of a pattern occurring for that individual. Three ways to adjust the support to increase the speaker's accuracy in letter selection are:

   a) angle the device to compensate for the movement pattern;
   b) use a device with a keyguard; and
   c) provide increased pressure to the side of the hand, wrist or arm where veering occurs.

9. **Initiation problems: The person using facilitation shows difficulty in starting the movement or indicating readiness to begin pointing.**

   Give the person frequent invitations to share his/her thoughts. During facilitated interaction, give verbal encouragement to continue with the communication. Give positive feedback to the individual that his/her communication has been successful.

10. **Impulsivity: The person typing moves too fast and often starts pointing before the question is clear.**

    Give consistent backward pressure so that the person needs to push against your hand to make a letter selection. Slow the person's movement down and encourage a rhythm pattern that fosters a controlled, even pace.

11. **Proximal instability: The person's shoulder and trunk position is unstable. While facilitating, the person may flop, lean, rock, or slip out of the chair. His/her arms and/or legs may swing or flail.**

    Explore optimal seating positioning for the person. Use chairs that are comfortable but do not allow the person to slouch. Also encourage a position where the person's feet can rest quietly on the floor. Tailor-style sitting (cross-legged on the floor) is a possibility for small children. Give physical support as necessary so that the shoulder and trunk area remain stable. This can often be accomplished with a firm hand on the shoulder.

12. **Reduced proprioception: The person typing may overshoot the intended target or stop short of the target, indicating a lack of understanding of distance or position in space.**

    This is hard to diagnose. Rocking may be a sign that poor proprioception is an issue. Explore the possibility of practice with weights to increase the person's awareness of positioning. Give verbal feedback to help build understanding of where he/she is in relation to the target.

It is important to note that the above issues typically occur in combination with one another. Certain issues will dominate a person's overall style of movement, but any given situation can affect how the issues combine. For instance, many people who use facilitation have shown both low muscle-tone and high muscle-tone in the same interaction. The facilitator needs to understand these issues and be ready to support the speaker to build and maintain successful communication.

5. PRACTICE POINTING

"Pointing is a skill that we teach all of our kids....poking into play-doh is using your index finger and doing some of the finger plays that kids do are all working on index finger isolation....all of that builds into some of the skills that they need in order to be able to do the spelling."

--Zan Currin
"A Part of Our Life": Facilitated Communication with Pre-School Age Children

Each of the people on the videotapes are successful communicators because there was time to practice. For young children, this may have meant using pointing to do activities other than spelling, like poking at play-doh, playing a pop-up game, or operating the dispenser of liquid soap. This also may mean taking time to practice rote spelling, such as name and address, so that movement to the letters become easy and more rhythmic. There are many skills to practice, such as looking at the letters, being accurate in letter selection, staying with a task until done, and being able to move with less support. The more a person has the opportunity to work on these skills, the better chance he/she has of being successful.

6. MONITOR EYE CONTACT WITH KEYBOARD

"It's very important for people to look at the target. They have to do that in order to be accurate. Also, if a person looks at the target we can begin to provide less physical support as the person types and the person goes on to be more independent."

--Doug Biklen
"A New Beginning": Facilitated Communication for Adults

As you watch the videotapes, you will hear facilitators remind the people that they are working with to look at the letters. From the start, encourage eye contact with the keyboard. This will discourage over dependency on the physical support and encourage the individual to be responsible for the communication and work toward independence. One can encourage this looking behavior with verbal comments and/or light touches to the head or neck area. The facilitator should stop the interaction if the individual looks totally away, or the letterboard is completely outside the individual's visual field. Eye contact with the keyboard is also encouraged by fading back physical support as rapidly as possible.

7. FADE TO MINIMUM SUPPORT

> "When you feel it getting easy or when you see the student's attention begin to wander a little bit more, then it means that it's really time to move back."
>
> *--Sue Harms*
>
> *Facilitated Communication: "In the School Years"*

Right from the beginning of facilitation training, try to establish that minimum level of support at which the individual can give a response successfully. More support may allow the person to become dependent on the facilitator. Less support would cause frustration for both the facilitator and the person trying to type. From that point of minimum support, the facilitator should foster an idea of increased independence. Fading, then, is the process of changing support to encourage independence.

The long term goal of facilitation is independent typing. This means typing without physical support. It also means taking responsibility for and being able to manage communication interactions. People who use facilitation need to gain control of the movement to the spelling device. They also need to be able to initiate conversation, establish the topic, and let others know if they have been misunderstood. The following are suggestions to help facilitators and people using facilitation develop independence:

Physical

1. Begin with more than one facilitator.
2. Talk about independence from the very beginning.
3. Build confidence of the person in being able to be independent.
4. Provide a consistent practice time.
5. Work first with routine, predictable information.
6. Look for ways to change support.
7. Identify roadblocks to independence; develop strategies.
8. Solicit the ideas of the person using facilitation.
9. Be patient, supportive, and expectant.

Communicative

1. Develop clear signals that indicate the need to talk.
2. Develop a way that the person typing can interject in a conversation.
3. Foster use of key words to change topic.
4. Foster use of spaces between words, and punctuation.
5. Foster self-correction when mistakes occur.
6. Develop a signal to be used as a protest strategy.
7. Develop strategies for conveying tone and mood in the interaction.

8. GIVE ENCOURAGEMENT

> "Sixteen year olds should be spoken to as if they're 16 years old. You know, to encourage them to keep going and to try to give them the confidence that you're going to stick with them and that you're going to be there with them and that they can do this work."
>
> *--Sue Harms*
> *Facilitated Communication: "In the School Years"*

As you view these videotapes, the positive regard of the facilitators for the people typing will be evident. You will hear comments that encourage the person to keep trying. It is important to realize that encouragement starts with valuing the person you are working with and seeing them as someone who has something to contribute...to you and to life. The positive comments, looks of encouragement, and commitment of time develop out of this.

Express your confidence in the person's ability to understand what you are doing. Try to speak in a typical, supportive way, avoiding unusual tones of voice (e.g. babying the person). Work with others to surround the individual in a positive, supportive environment, where the person's competence is accepted and respected.

Encouragement can also occur in the form of what is NOT done. If the person gets up in the middle of the session, slaps the table, screeches, pulls away, hits, or engages in other challenging behaviors, try to ignore these. Redirect the person to the task at hand. Avoid moralizing to the person, but show high expectations in a supportive fashion, saying, for example: "I know this isn't easy, but I want you to complete this before we stop."

❖ ❖ ❖ ❖ ❖

YOU ARE NOW READY TO VIEW **PART I** OF THE VIDEOTAPE. AS YOU MEET THE VARIOUS PEOPLE WHO COMMUNICATE THROUGH FACILITATION, LOOK FOR POINTS THAT WERE MADE THROUGHOUT THIS SECTION.

SECTION II

AFTER READING ABOUT THE METHOD AND SEEING IT ON VIDEOTAPE, YOU MOST LIKELY HAVE QUESTIONS. IN THE FOLLOWING SECTION ARE QUESTIONS COMMONLY ASKED ABOUT FACILITATED COMMUNICATION. USE THESE, OR DEVELOP YOUR OWN IN A DISCUSSION WITH OTHERS.

THE WORKSHEETS ON PAGES 19-21 ARE DESIGNED TO HELP YOU REFLECT ON THE VIDEOTAPE AND DEVELOP YOUR IDEAS. LOOK OVER THE WORKSHEETS AND DECIDE WHICH ONES YOU WILL DISCUSS, OR DUPLICATE FOR USE IN INDIVIDUAL OR SMALL GROUP ACTIVITIES.

COMMON QUESTIONS AND ANSWERS ABOUT THE METHOD

Neither the videos nor this guide can answer all of the possible questions that may arise about facilitated communication.

However, the following are some of the most often asked questions. They have been organized by topic and are divided between **Section II** and **Section III**. It may be helpful to have these as a reference guide during any group discussion of the method. Also refer to the bibliography in this guide for further readings.

WITH WHOM SHOULD IT BE TRIED?

1. ***What precursor skills would suggest a good candidate for facilitated communication?*** The method does not require that individuals have already passed particular educational or developmental milestones. For example, the method can be tried with individuals who have not yet revealed literacy skills. People can be asked to point to pictures or symbols and in fact may reveal literacy skills after being introduced to facilitation.

2. ***With regard to so-called "higher functioning" individuals (i.e. people with functional verbal abilities), is facilitated communication useful?*** We have found the method useful with people who have speech but whose speech does not enable them to carry on conversations, whose speech is limited to a few words and phrases, or with people who switch topics frequently, leaving the listener confused about what the person meant to say. Strategies for working with individuals who have echoed speech include working on set work that cannot be answered correctly with the person's usual echoes, typing to the person as he or she types back (this can help concentration and can free the person from typing echoes or repetitions of what the facilitator has said), and practice.

3. ***Who are good candidates for facilitated communication?*** Facilitated communication has been effective with people who cannot speak or whose speech is very limited and who cannot point independently or reliably. People with a variety of developmental disabilities may evidence these problems; we have worked with people with autism, cri-du-chat, Rett syndrome, cerebral palsy, Down syndrome, undifferentiated mental retardation, and other classifications.

4. ***Who would you work with first? In other words, presuming limited resources, with whom should one try facilitation first?*** We are not sure there is a good answer to this. Anyone who lacks an effective means of communicating deserves considerable effort by educators and family members to secure such abilities.

5. ***What about people who use sign language?*** Some individuals who use facilitated communication may also know and use some signs. Many individuals lack the motor planning skills to make most signs. Signs can be of limited use if there are not people around capable of reading the signs. For many people with limited sign use, facilitated communication has greatly broadened their ability to communicate.

6. ***How do you decide on using speech versus non-speech approaches?*** Its best not to choose. If a person can speak, he or she will likely want to work on speech in conjunction with pointing. The person may often indicate a preference for pointing to convey complex thoughts, and may prefer to use speech for one or two word utterances.

7. ***Is there any chance of harming the individual with facilitation?*** It is not harmful to teach people to communicate through pointing; it can be harmful if the facilitator overinterprets, does not monitor the person's eyes, facilitates when the person is looking away, is not sensitive to the possibility of guiding the person, and asks leading rather than clarifying questions.

8. ***What is apraxia and what is its significance for our understanding of facilitated communication?*** The term apraxia means "without action." It refers to absence of or difficulty with achieving voluntary action. Mostly what we observe with people who have developmental disabilities such as autism, Rett syndrome, Down syndrome, and other related conditions is *developmental dyspraxia.* That is, they can act, but voluntary actions are often disordered in some way. Specifically, developmental dyspraxia may include problems of initiating action (getting started); problems of stopping action (perseveration); impulsiveness; problems of modulating pace of action; inability to speak or speaking that is repetitive, automatic, or poorly articulated and of unusual pitch, rhythm, and tone; using two hands to do a task that others can do with one; taking longer than most people to learn a new task requiring motor planning; good ability to carry out routine activities and difficulty with new ones; poor proprioceptive awareness (e.g. knowing the place of one's body in space, knowing where one's arm is in order to move it; knowing where a finger in relation to other fingers in order to isolate it); difficulty isolating extremities from trunk (e.g. arm from upper body, in which case pointing may involve moving whole upper body toward a target); problems with sequencing actions (e.g. in typing this is revealed in sequencing problems with letters and words); and greater difficulty in carrying out multiple step activities than single step ones. In other words, apraxia or dyspraxia refer to the absence of or difficulty with voluntary action, especially with activities that involve new, complex motor planning. Physical support to slow down pointing can help a person overcome impulsiveness, problems of pacing action, and can help a person stop one action and go on to another (e.g. pull back and go for another letter or picture). Similarly, a hand on the forearm, elbow, or shoulder, or merely sitting next to a person typing can help the person to focus on the task at hand, helping the person to initiate action and to relax enough to get sequencing correct.

KNOWING THAT IT IS REAL: LOOKING AT RESEARCH.

9. ***How do you know that the communication is coming from the person who has the disability?*** The most obvious indicators are when people achieve independent typing or when individuals type information that was not known to the facilitator but which can be verified. Often individuals will be able to type their own name, familiar phrases, or answers to math problems before going on to type independent conversational communication. Other indicators are revealed in a

portfolio of a person's typing through distinctive stylistic features such as use of creative spellings, recurrent phrases or words, recurrent themes or topics, sentence structure and so forth.

10. ***Why might some approaches to validating facilitated communication not work well?*** It is important to remember that confrontational testing may undermine confidence and certain simple naming tasks may simply reveal a person's word retrieval difficulties. Failure on one test does not preclude the person passing another test. For further discussion, see Biklen, (1993b).

11. ***How do the literacy abilities revealed through facilitation change our understanding or definition of autism? How about other disabilities, such as mental retardation?*** Clearly, some people have been thought to be retarded when in fact they were not; they had problems of expression that made them appear retarded. It is not yet known for how large a group this will prove to be the case.

12. ***If a person fails to validate his or her communication in a formal test, should efforts to use facilitation with the person be stopped?*** No. Most individuals with whom we are working do not have experience with test taking, have problems such as word retrieval and failed confidence and/or may be offended by being tested. Failing a test does not mean the person cannot communicate, it only means the person failed the test. We have seen instances in which individuals have failed various message passing tests but have been able to prove their ability to communicate by conveying other information not known to the facilitator or by learning to type independently.

13. ***What do we know about the reading abilities of young children with autism or other developmental disabilities? What do we learn from the literature? What do we learn from facilitation?*** Clearly, children have different literacy skills. Some children will not have yet developed reading skills but may be working on it, even though they may not be able to show what they know without facilitation. Others may have developed skills by being taught or by observing words around them. This is consistent with the literature on emergent literacy (e.g. Koppenhaver et al., 1991).

DEVELOPING PEOPLE'S SKILLS

14. ***Why is confidence an important ingredient in a person's success with facilitation?*** Not surprisingly, people who have had a history of difficulty with motor planning will lack confidence in their ability to carry out new tasks. Imagine what it must be like to have significant problems with motor planning and indeed any kind of voluntary action, and to have this problem from a very early age, in effect never having had success in getting your body to do what you wanted it to do when you wanted it? And imagine what it would be like to be evaluated on the basis of your nonresponsiveness or your impulsiveness? Hence the importance of being supportive to help the person develop confidence that he or she <u>can</u> develop the ability to be successful in communicating through typing.

15. ***Is it important for individuals to have printed feedback as part of the facilitated communication process?*** This is not always required, but is very helpful for the facilitator to follow what is being typed.

16. ***What kind of equipment do you recommend?*** A variety of equipment may be tried. Some considerations are portability, durability, whether there is a typed output or display of what has been typed, whether there is a key guard to protect individuals from typing multiple rather than single letters or numbers, cost, and requirements of the setting in which the person may be communicating (e.g. use a laminated card in a swimming pool). For further discussion, see Appendix III (p. 34).

17. ***How do you teach individuals to ask questions instead of facilitators always asking the questions?*** This may not be an issue as some people will ask questions on their own. Others will simply need to be encouraged to do so. Provide opportunities for practice.

18. ***How much resistance is needed from the facilitator, and how do you judge that?*** The purpose of resistance is to slow down the person while pointing and to assist the person in overcoming impulsive pointing. Some individuals will require strong resistance to slow down or to avoid rapid, impulsive pointing. You will have to explore this individually.

19. ***Why is it necessary to pull back from errors? <u>Is</u> it necessary?*** This is a strategy during the early stages of facilitated communication training when the person is using set work exercises with predictable answers. Be careful not to pull back so quickly that you do not give the person an opportunity to surprise you with answers you may have not anticipated. But if you are getting clearly echoed words, nonsense words, numerous consonants or vowels in a row, or other impossible-to-understand selections, pull back and ask the person try again.

20. ***How is it best to deal with the problem of low muscle tone?*** Encourage individuals to practices the skills needed for pointing to communicate. This includes isolating the index finger, pointing, and pulling back after selections. This may not improve muscle tone, but individuals can improve at these skills.

21. ***Are there particular strategies for helping people to generalize facilitation to more than one facilitator?*** Yes! Provide encouragement, be insistent and persistent, and try to generalize to multiple facilitators from the very first introduction of facilitated communication.

22. ***How do you deal with tactile defensiveness?*** We have found that this is not a major problem. Most people who do have sensitivities to touch seem able to work with facilitators. Often firm support is more tolerable than light support. Also, the person may be encouraged to bring his or her arm <u>to</u> the facilitator's hand; it is often easier to touch than to be touched.

23. ***What should you do when people demonstrate difficult behavior during a facilitation session?*** Be persistent. Ask the person if he or she can tell us how we should deal with the behavior.

24. ***How can people become independent in their typing?*** Facilitators and people with disabilities need to work on this together. Factors related to success include: motivation, opportunities to practice, trying to type with no support and then providing more and more support until the facilitator finds the least amount of support the person

needs in order to type, practicing on copying and other simple tasks first --- try one's own name and math problems or multiple-choice activities ---, and time. (For further information, see Chadwick, 1993).

25. ***Can peers become facilitators?*** Yes! Peers will need training, but they can learn to be facilitators.

26. ***Is there a point at which you decide to stop trying facilitated communication?*** This is a highly individualized question that broaches on educational philosophy. Usually, when something is "not working" there is something happening and we need to look at the detail of what is happening. Also, often, adjustments may need to be made in the approach. And there will come a point or there will be specific reasons for not continuing facilitation.

27. ***What do you do if a person starts typing and then stops?*** Keep talking to the person about it. Keep encouraging the person to communicate, even if by just making selections in everyday situations. And sometimes, people will stop if they feel the communication tasks are repetitive or too simple minded and boring; try to make the topics of communication more interesting.

28. ***How do you use facilitated communication in functional, everyday situations?*** To communicate throughout the day, people need facilitators, communication devices, people to listen to them, and opportunities in which to communicate. Most importantly, the people around the person with a disability must recognize that not being able to speak is not the same as not having something to say.

29. ***Why don't you use devices with whole words preprogrammed?*** Sometimes we do. These can be helpful in situations where a person knows he or she may need certain phrases. However most people also want to have the full alphabet available because this guarantees access to any words they might want.

30. ***How long should a typical facilitation session last?*** This varies. There is no hard and fast rule. Facilitated communication training may occur in a series of brief attempts or in hour and multi-hour sessions.

31. ***Is it important for individuals to have verbal feedback on what they are typing?*** This is generally not necessary.

32. ***Should you accept misspellings as communication? When should you correct misspellings?*** For this and other educational matters, you will probably want to apply the same requirements or approaches that you would use with speaking individuals.

33. ***What are the qualities of a good facilitator?*** Generally these are similar to the qualities of a good friend, good teacher, and good parent; the method requires persistence, encouragement, optimism that the person can learn to communicate by pointing, self reflection, good listening skills, a willingness to put one's own ego aside and to be supportive of the other person, and a strong commitment to foster the person getting control of his or her communication.

34. ***When you begin using facilitated communication, is this better done in a classroom or in a speech therapy office?*** Both settings have been used effectively.

35. ***How do you know whether to use the left or the right hand?*** Hand the person an object. Usually, the hand extended to grab the item is the person's dominant one.

36. ***What if you begin using facilitation and it doesn't work?*** Talk to others who are using the method. Examine a videotape of your use of the method for review.

37. ***Does it matter what kind of letter display is presented to the individual?*** We have used both sequential displays (ABCDE...) and the standard typewriter displays (QWERT...). Some people are able to use them both interchangeably without difficulty.

38. ***What is set work? What is its purpose for facilitated communication? What are the principal types of setwork formats?*** Set work is activities with predictable answers. We use setwork in the early stages of facilitation training so that we can get a sense of the individual's physical movement to the target and the kinds of support required. Setwork also enables the person to build confidence in his or her ability to communicate in this fashion before going on to open ended communication. Typical kinds of set work include matching activities, spelling words, yes/no and true/false questions, copying, fill-in-the-blanks, and math problems.

❖ ❖ ❖ ❖ ❖

SECTION II

Worksheet 1

Choosing a Candidate

Concerning the question of choosing a candidate for facilitated communication, the video talked about no speech or limited speech combined with a pointing response which is unreliable. It encourages you to make a decision based on the person's actual behavior rather than on his/her label. It is helpful to talk with others about people that you are thinking could benefit from facilitated communication. Using the questions below, take some time to share your thoughts in a small group setting.

How would you describe the people in the videotape who use facilitation?

How do these characteristics compare with the person(s) that you think might benefit from the method?

Are there other factors which lead you to think the method is appropriate?

Are there concerns that lead you to think that your person might not be a good candidate?

SECTION II
Worksheet 2

Simulation

It is often helpful in learning about facilitated communication to have the opportunity to "feel" what it is like to hold another's hand, wrist or forearm. The following process is a guided simulation to help you further understand what is meant by resistance. It will also help you develop the kinds of questions appropriate for beginning with an individual. You will need to pair up with another person. One of you will be the facilitator and one of you will be the person needing support. A letterboard is provided on the following page for this exercise. As each of you "play the role", you will need to follow the guidelines given below:

Person Needing Support: Before you begin, choose one of the hand function issues outlined in Section I (Pages 8-9). You may want to portray the person you discussed in Worksheet 1. Think about how that person moves. Do not tell the facilitator what movement pattern you will be using. Try to use the movement pattern throughout the time that you will be playing this role.

Facilitator: Before you begin, think of questions which are predictable, that is, where you have a sense of what the answer might be. Think of how you will introduce the method to the person you are working with. What will you say before you hold the person's hand? Make decisions about where to place the letterboard, what side to sit on, and how to position yourself (sit or stand, etc.)

As you work together, movement should always be initiated by the person needing support. The facilitator resists the movement and pulls back after each letter selection. Is there enough resistance and pullback to promote an even, rhythmic pattern?

After you have facilitated for a few minutes, think about the following questions:

Facilitators: What were your eyes doing? What was your mind doing? Did you take time to look at the person you were supporting and monitor the whole interaction or were your eyes "glued" to the letterboard? What did you think about when the facilitator made letter selections different than what you expected? How did you know that the supported person was making the selections?

Supported Person: How did it feel to have someone touch you? How did the resistance feel? What was it like to have to spell your message out? What were you thinking when you made a mistake? How did you feel when you sensed that you were not understood?

Share your ideas and feelings about your experience with your partner and then with the larger group. If there is time, switch roles so that you have time to experience both roles.

0	1	2	3	4	5	6	7	8	9
			A	B	C		D	E	
YES									*STOP*
			F	G	H		I	J	
MORE									*NO*
			K	L	M		N	O	
		P	Q	R	S		T	U	
			V	W	X		Y	Z	
DELETE		SPACE			.		,	?	!

SECTION II

Worksheet 3

Respectful Attitudes

One of the basic tenets of facilitated communication is that all people deserve to be treated respectfully and that it is important to keep open the possibility that people will surprise those around them with what they observe, feel, and know. In each of the videotapes, the individuals videotaped show great respect for each other.

In the videotape that you watched, how is personal respect conveyed or otherwise revealed?

In the videotape that you watched, how did teachers, parents, friends or others handle difficult behavior by a person with a disability?

YOU HAVE HAD TIME TO READ ABOUT FACILITATED COMMUNICATION, SEE IT ON TAPE, TALK ABOUT IT, AND PERHAPS GO THROUGH THE SIMULATION AND "FEEL" WHAT IT MIGHT BE LIKE. TAKE TIME NOW TO WATCH PART II AND SEE HOW IT HAS CHANGED THE LIVES OF PEOPLE WHO USE IT EVERY DAY FOR COMMUNICATION.

SECTION III

AS WITH PART I OF THE VIDEOTAPE, YOU ARE INVITED TO REFLECT ON PART II AND SHARE YOUR QUESTIONS AND IDEAS WITH OTHERS.

ON THE FOLLOWING PAGES, YOU WILL FIND COMMON QUESTIONS AND WORKSHEETS THAT FOCUS ON USING THE METHOD TO HELP DEVELOP PEOPLES' LIVES.

MORE COMMON QUESTIONS AND ANSWERS ABOUT THE METHOD

USING IT IN THE REAL WORLD

39. ***How do you deal with emotional content that people reveal when using facilitated communication?*** Talk to people with the same sensitivity you would with a person who can speak. Understand that sometimes being listen to is enough -- your role as a facilitator isn't to "make everything better."

40. ***Does behavior improve as a result of using facilitated communication?*** We have not done research on this although it certainly appears that individuals' behavior improves. For example, many people with whom we work are now able to sit through hour-long academic classes in school; this was previously not thought possible for most of them.

41. ***Are people able to tell you why they are upset or were upset?*** Yes, often they are. Sometimes the explanation may follow some time later after a behavioral outburst.

42. ***What do you do when someone reports abuse, sexual or physical? What are some of the complications that should be considered in relation to abuse charges?*** Some individuals have reported that they were abused. Some of these charges have been corroborated by confessions and/or other evidence, including physical evidence of abuse. Other charges have proved unfounded. It is important to remember that any instance of abuse allegation is complex, whether it involves facilitated communication or not. If there is reason to suspect that a person has been the target of abuse, this should be reported to legal authorities. Legal authorities must then determine: 1) if the allegations originated with the person with the disability --- we recommend asking a facilitator unfamiliar with the prior tclaim to facilitate to see if the person repeats his or her allegations; and 2), if the allegations *were* typed by the individual, then are they true?

43. ***How can people using facilitated communication be supported to participate in regular academic classrooms?*** Until individuals become independent in their typing, they will need facilitators with them in every aspect of school life. Peers may be enlisted as facilitators, but people will also need facilitators fulltime during academic instruction. Typically, a number of individuals in the classroom can be facilitators, including the head teacher. Many students using facilitation will need some accommodations in the number of math problems or other work required within lessons due to the extra time that it takes for individuals to communicate using facilitation.

44. ***What are the funding sources for equipment?*** This will vary by community and state. Federal law requires that if school age children need a communication device in order to participate in a school program, then it must be provided.

45. ***Will people's speech increase when they are using facilitated communication? Or should we expect that their speech will decrease?*** We see no evidence that functional speech will diminish. Some individuals are able to say letters or words just

prior to or after typing them, and some people are able to read sentences aloud after typing them. For some individuals, their amount of repetitive, non-functional speech decreases as they become more skilled in communicating through typing.

46. ***How do you deal with challenging behaviors?*** Facilitated communication does not remedy all difficulties. But with facilitation, you can often learn what the person knows about why he or she behaves in certain ways and what might help precipitate a change; if not, considerations are to be sensitive, firm, and supportive.

47. ***What are the implications of facilitated communication for Individual Education Plan (IEP) goals? What IEP goals might be developed relative to facilitated communication?*** Virtually everyone using facilitated communication in schools should be working on becoming independent in typing; this can be an IEP goal. In regard to other IEP goals, facilitated communication is merely a supportive method.

48. ***How do you motivate people to use facilitated communication at home?*** Examine all of the situations in home life in which the ordinary person of the same age wants and needs to communicate. Encourage communication in these situations (e.g. selection of television programs or activities, selection of the menu, selection of clothing, games, and conversations.) Remember that facilitated communication should not be forced in those situations where the individual already communicates clearly and effectively.

49. ***What kinds of behaviors might change as a result of facilitated communication?*** Presumably, difficult behavior that is linked to frustration at not being able to communicate effectively will diminish. Similarly, behavior that was previously intended to communicate (e.g. a tantrum to say no) may be replaced by pointing or typing.

50. ***If apraxia is a problem that extends beyond communication, how might facilitation assist other kinds of physical activities?*** Often, people may have difficulty getting started with an activity; a hand on the shoulder can sometimes allow the person to initiate activity.

❖ ❖ ❖ ❖ ❖

SECTION III
Worksheet 1

Making It Work

Facilitated communication is not a "treatment"; it is a means of communicating. For this reason, people using facilitation as their means of expression need lots of opportunities to learn how to do it and to work on becoming independent. Also, they need people who are supportive of their communicating in this alternative way: people who will be their facilitators; people who want to hear what they have to say; people to listen and with whom to converse; people who will help make sure that they have equipment on which to converse; people who will take the time to make it work.

In the video that you watched, what did people around the person with a severe communication impairment say about what they do to make the method work?

In the video that you watched, what are some of the activities, situations, times when facilitation was used?

If you are working with or planning to work with someone who has a severe communication impairment, what are some of the ways or opportunities you might take to make facilitation work?

SECTION III
Worksheet 2

Fostering Literacy

Literacy skills are learned. Yet often, we develop our reading and math skills as well as our knowledge base informally, that is without formal instruction; for example, through television, by reading for pleasure, by looking at street signs and magazines or newspapers, by looking at grocery labels, and through advertisements.

In the video you watched, what opportunities were there for the person with a severe communication impairment to develop or improve his or her literacy skills?

In the settings in which you work, how are literacy skills fostered? How might opportunities for literacy development be improved?

SECTION III
Worksheet 3

Facilitated Communication in Inclusive Settings

Each of the videos shows people using facilitated communication in inclusive settings, such as homes, community locations (e.g.library, restaurant, and grocery store), and schools. Many people ask, however, "How do you make inclusion work?" Use the following questions to guide your discussion.

In the video that you watched, what are teachers, parents, friends, or others doing to make the setting inclusive?

In what ways do inclusive settings create positive circumstances for using facilitated communication?

What kinds of adaptations might be necessary to foster the fullest possible inclusion of a person using facilitated communication into every aspect of life in a given setting?

What questions do you still have about how to make inclusion work?

SECTION III
Worksheet 4

Changing Roles

Many of the people in the videotapes talk about how their lives are changing as a result of facilitated communication. (Whether you have been using facilitated communication for some time or you are about to begin, this is a topic that is likely to generate a great deal of discussion.)

In the videotape that you watched, how were the lives of people with severe communication impairments affected by their use of facilitated communication?

In the videotape that you watched, how were the lives of teachers, parents, friends, and others affected by the fact that people they knew were using facilitated communication? What did these people say about this?

How do you think your life might be changed by becoming involved in using facilitated communication? *or,* how has your life been changed by your involvement in using facilitated communication?

SECTION IV

APPENDICES AND BIBLIOGRAPHY

APPENDIX I: RESOURCES FOR SETWORK

Ideas for Preschool Age Children

- Toy choices
- Food Choices
- Activities incorporating preschool concepts
- Number Games
- Creative play where they can decide on characters and actions
- Books on favorite topics
- Making schedules
- Activities where they can direct your actions
- Photo album of class and/or family life

Ideas for School Age children

- Type own name, family members' names, names of classmates
- Multiple choice
- Matching
- Crossword Puzzles
- Activities incorporating school age concepts
  - Spelling words
  - Math problems
  - Fill-in-the-blanks
  - Comprehension questions
- Making schedules
- Books on Favorite topics
- Activity choices

Ideas for Adults

- Making Schedules
- Making menus
- Reading sections of the newspaper
- Reading magazine articles
- Photo albums
- TV shows
- Natural questions on an interested topic
  - current events
  - family/friends
  - sports
  - music
  - cars
- Activity choices

APPENDIX II:
PROBLEM-SOLVING FACILITATED COMMUNICATION

PROBLEM	SUGGESTIONS
No response	☼ ask a harder question ☼ change support ☼ position letterboard lower ☼ give visual support ☼ give further explanation
Extra letters; reader can't understand message	☼ change support ☼ give more resistance ☼ talk about using spaces between words ☼ ask to try again ☼ practice at a lower level on the "ladder" (page 5)
Resists touch	☼ give positive verbal reassurance ☼ give further explanation of the purpose of facilitated communication ☼ build success with a single pointing response to answer a yes/no question or point to a picture ☼ model technique with their hand on yours
Hits, bites, scratches	☼ remain calm ☼ solicit their ideas about what is going on; encourage them to communicate ☼ change level of support ☼ anticipate behavior; solve issues that are known from previous situations
Answers verbally	☼ acknowledge verbal answer; suggest writing it as well ☼ build on verbal answer to ask the next question ☼ ask for verification of verbal response with written mode
Spells answer inconsistent with other behavior	☼ verify spelled answer ☼ follow spelled answer and look for a pattern of intent

APPENDIX III: EQUIPMENT

It is best when starting facilitation with someone to explore various types of equipment. This helps you to select a device that assists with the hand function issues. It will also enable you to see what is preferable to the person who is typing. Some of the common equipment options used include:

- ☼ letterboards of various sizes,
- ☼ computers
- ☼ electric typewriters
- ☼ pocket organizers
- ☼ Canon Communicator
- ☼ ABOVO PCD
- ☼ Crestalk

When using these various devices, try to answer the following questions: Does it need to be portable? How will the person access the device? Should it have a keyguard to assist the person's accuracy? How large should the letters be? Is the person more comfortable with QWERTY letter arrangement or ABC arrangement? Are the keys hard to press? Does your person require a light touch? Do you need a visual display of what is being typed? Is a printout of the message necessary or helpful? Does the person typing seem to like one device over another?

There is no one perfect device and you may end up using more than one device to meet the need of various situations. By focusing on the above questions and deciding which issues are most important, you will be able to conclude which equipment is most effective for that person.

It is important to remember that as a person becomes fluent in typing, he or she will be able to state preference for one device or another.

❖ ❖ ❖ ❖ ❖

MAKING A SPELLING BOARD

On page 21, a letterboard is provided as a model. If you want to make your own letterboard, take the following points into consideration:

- ☼ A letterboard is more than just letters. It should also include numbers, punctuation (.?!), and a "space bar" so that the person can indicate the beginnings and endings of words and sentences.
- ☼ The letterboard should also have a delete key so that the person can correct mistakes when they happen.
- ☼ It is often helpful to add words or phrases that the person frequently types. This speeds the communication by offering another way to say it.
- ☼ The letter arrangement for letterboards can be either ABC order or QWERTY arrangement, as with typewriters and computers.

❖ ❖ ❖ ❖ ❖

BIBLIOGRAPHY

Attwood, T. & Remington-Gurney, J. (1992). Assessment of literacy skills using facilitated communication. In C.E. Van Kraayenoord (ed.) *A survey of adult literacy provisions for people with intellectual disabilities.* Brisbane, Australia: University of Queensland, Schonnel Special Education Research Centre.

Barron, J. & Barron, S. (1992) *There's a boy in here.* NY: Simon & Schuster.

Biklen, D. (1993a). *Communication Unbound.* New York: Teachers College Press.

Biklen, D. (1993b). Notes on validation studies of facilitated communication. *Facilitated Communication Digest, 1*(2), 4-6.

Biklen, D. (1992). Typing to talk: Facilitated communication. *American Journal of Speech-Language Pathology, 1*(2), 15-17.

Biklen, D. (1992a). Autism orthodoxy versus free speech: A reply to Cummins and Prior. *Harvard Educational Review, 62*(2), 242 - 256.

Biklen, D. (1992b). Facilitated communication: Biklen responds. *American Journal of Speech-Language Pathology, 1*(2), 21-22.

Biklen, D. (1992c). *Schooling Without Labels: Parents, Educators, and Inclusive Education.* Philadelphia: Temple University Press.

Biklen, D. (1990). Communication unbound: Autism and praxis. *Harvard Educational Review, 60,* 291-314.

Biklen, D., Corrigan, C., & Quick, D. (1989). Beyond Obligation. In D. Lipsky & A. Gartner. *Beyond Special Education.* Baltimore: Paul Brookes.

Biklen, D., Morton, M.W., Gold, D., Berrigan, C., & Swaminathan, S. (1992). Facilitated communication: Implications for individuals with autism. *Topics in Language Disorders, 12*(4), 1 - 28.

Biklen, D., Morton, M.W., Saha, S.N., Duncan, J., Gold, D., Hardardottir, M., Karna, E., O'Connor, S., & Rao, S., (1991). "I AMN NOT A UTISTIVC OH THJE TYP" ("I'm not autistic on the typewriter"). *Disability, Handicap & Society, 6*(3), 161-180.

Bogdan, R. (1980). What does it mean when a person says, "I am not retarded"? *Education and Training of the Mentally Retarded, 15,* 78-90.

Bogdan, R. & Biklen, S. (1982). *Qualitative research for education: An introduction to theory and methods.* Boston: Allyn & Bacon.

Calculator, S.N. (1992). Perhaps the emperor has clothes after all: A response to Biklen. *American Journal of Speech- Language Pathology, 1*(2), 18-20.

Calculator, S.N. (1992). Facilitated communication: Calculator responds. *American Journal of Speech-Language Pathology, 1*(2). 23-24.

Calculator, S.N., Singer, K.M. (1992). A Preliminary Study of Validation. *Topics in Language Disorders, 13*(1), ix-xvi.

Chadwick, M. (1993) Achieving independent typing. *Facilitated Communication Digest, 1*(2), 3-4.

Crossley, R., & McDonald, A. (1980). *Annie's coming out.* NY: Penguin Books.

Crossley, R. (1992). Lending a hand: A personal account of the development of facilitated communication training. *American Journal of Speech-Language Pathology, 1*(3), 15-18.

Crossley, R. & Remington-Gurney, J. (1992). Getting the words out I. *Topics in Language Disorders, 12*(4), 29-45.

Crossley, R. (1992). Getting the words out II. *Topics in Language Disorders, 12*(4), 46-59.

Cummins, R.A. and Prior, M.P. (1992). Autism and communication: A response to Biklen. *Harvard Educational Review, 62*(2), 228-241.

Damasio, A.R. & Maurer, R.G. (1973). A neurological model of autism. *Archives of Neurology, 35*, 777-786.

DEAL Communication Centre (1992). *Facilitated Communication Training.* Melbourne, Australia: DEAL Communication Centre.

Donnellan, A.M., Sabin, L.A. & Majure, L.A. (1992). Facilitated Communication: Beyond the quandary to the questions. *Topics in Language Disorders, 12*(4), 69-82.

Eastham, M. (1992). *Silent Words: A Biography.* Ottawa: Oliver-Pate.

Grandin, T. & Scariano, M.M. (1986) *Emergence Labeled Autistic.* Novato Arena Press.

Hall, P.K. (1992). At the center of controversy: Developmental apraxia. *American Journal of Speech-Language Pathology, 1*(3), 23-25.

Johnson, I. (1989). "Hellish difficult to live in this world": The unexpected emergence of written communication in a group of severely mentally handicapped individuals. *Journal of Social Work Practice, 4*(1), 13-30.

Koppenhaver, D.A., Coleman, P.P., Kalman, S.L. and Yoder, D.E. (1991). The implications of emergent literacy research for children with developmental disabilities. *American Journal of Speech-Language Pathology, 1*(1), 38-44.

Lakoff, G. & Johnson, M. (1980). *Metaphors we live by.* Chicago, Illinois: University of Chicago Press.

McLean, J. (1992). Facilitated communication: Some thoughts on Biklen's and Calculator's interaction. *American Journal of Speech-Language Pathology, 1*(2), 25-27.

Miller, N. (1986). *Dyspraxia and its management.* Rockville, MD; Aspen, 155-194.

Mirenda, P. & Mathy-Laikko, P. (1989). Augmentative and alternative communication applications for persons with severe congenital communication disorders: An introduction. *AAC Augmentative and Alternative Communication, 5*, 3-13.

Nolan, C. (1987). *Under the eye of the clock.* New York: St Martin's Press.

Oppenheim, R. (1974). *Effective teaching methods for autistic children.* Springfield, IL: Charles C. Thomas.

Reddy, M. (1979). The conduit metaphor. In A. Ortony (ed.) *Metaphor and thought.* New York: Cambridge University.

Robin, D.A. (1992). Developmental apraxia of speech: Just another motor problem. *American Journal of Speech-Language Pathology. 1*(3), 19-22.

Schawlow, A. & Schawlow, A.L. (1985). The endless search for help. In M.F. Brady & P. Gunther (eds.) *Integrating Moderately and Severely Handicapped Learners: Strategies that Work.* Charles C. Thomas, Springfield, Ill.

Schubert, A. (1992). *Resource guide on facilitated communication.* Boston: Adriana Foundation.

Wheeler, D.L., Jacobson, J.W., Paglieri, R.A., & Schwartz, A.A., (1993). An Experimental Assessment of Facilitated Communication. *Mental Retardation. 31*(1), 49-60.

ORDER FORM

5-VIDEO MULTIMEDIA TRAINING PACKAGE AND DISCUSSION GUIDE
from the
Facilitated Communication Institute
Syracuse University

Developed by Academy Award winning producer Gerardine Wurzburg, and State of the Art Inc.

_____ ***"We Have a Lot to Offer": An Introduction to Facilitated Communication***
_____ ***"A Part of our Life": Facilitated Communication with Pre-School Age Children***
_____ ***Facilitated Communication "In the School Years"***
_____ ***"A New Beginning": Facilitated Communication for Adults***
_____ ***Facilitated Communication with Family and Friends***

Each video is $50.00. The PAL version (for European VCRs) is $60.00. The entire package can be purchased for $200 (PAL version: $240) -- *but only if purchased at one time as a package.*

❑ PLEASE SEND INFORMATION ON PUBLICATIONS, VIDEOTAPES AND NEWSLETTERS AVAILABLE THROUGH THE FACILITATED COMMUNICATION INSTITUTE.

Name

Address

City State/Prov. ZIP/P.C. Country

Phone FAX

Amount enclosed:

Checks and Money Orders are payable to **SYRACUSE UNIVERSITY.** Purchase orders are also accepted. Telephone orders are not accepted. Mail to: ***Facilitated Communication Institute, Syracuse University, 370 Huntington Hall, Syracuse, NY 13244-2340.***